



Adherence Support

Program Manual

**Written and compiled by Jennifer Lorvick
with assistance from the Action Point staff**

Acknowledgments

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Quotes by Action Point clients and providers are derived from qualitative data made available by Dan Ciccarone, MD,MPH, who is conducting an evaluation of the program.

Action Point Program Manual

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Section 1: History and Description of the Action Point Program

Program History

In January 1998, Mayor Willie Brown convened a Citywide Summit on HIV/AIDS in San Francisco. The aim of the summit was to recommend changes to local HIV/AIDS policy, in response to the new challenges and opportunities engendered by the advent of antiretroviral therapy (ART). The summit brought together a wealth of expertise in HIV prevention, treatment and research offered by representatives of community agencies, the health department and academic institutions in San Francisco. One of the recommendations arising from the summit was to develop two “strategically located drop-in centers called Action Points.”

Action Point Centers will provide services to people having problems with adherence to combination therapy and who are currently homeless and marginally housed. Those services include adherence tools and adherence counseling for both combination therapy and prophylaxis, and counseling on developing and maintaining a health management strategy based on the harm reduction model.

**Recommendation of the Subcommittee on Adherence
Mayor’s Summit on HIV/AIDS, January 1988**

After a community planning process that utilized the expertise of advocates, researchers, clinicians and members of the Department of Public Health, the Action Point Adherence Project began on March 15, 1999 at the offices of the San Francisco AIDS Foundation. The project opened its present storefront site on July 6, 1999. Action Point 1 (AP) is centrally located in a poor urban neighborhood. It co-exists with pawn shops, liquor stores, cheap hotels and round-the-clock street activity on Sixth Street in the South of Market area.

Action Point I Mission Statement

The Action Point Adherence Project is a community-based, collaborative project of the San Francisco Department of Public Health and the San Francisco AIDS Foundation that seeks to support HIV infected urban poor to develop the skills to adhere to anti-retroviral medication. We provide a non-judgmental harm reduction program that advocates, in partnership with our clients, to overcome the competing life priorities that often undermine successful adherence.

Part of what made AP possible was a favorable political and economic climate in San Francisco. The City had already made the commitment to provide ART to individuals with HIV regardless of insurance status. The Bay Area was experiencing an economic boom due to the growth of 'dot-com' industry. Finally, the program had the backing of the Mayor who literally wrote it into the City's budget. From its inception, AP was funded through relatively unrestricted local general funds. Unlike most medical and social services, the program doesn't have to bill per patient or per service. This lack of external requirements has enabled the program to be flexible, client-centered and creative in its approach.

It was actually remarkably straightforward. I mean, the mayor said, "I like this idea -- I wanna adopt it." And he made speeches about it. And funding happened.

AP provider

Program description

AP is a joint project of the San Francisco Department of Public Health and the San Francisco AIDS Foundation. It provides adherence support to HIV-infected people who take or are preparing to take anti-retroviral medications. Adherence support services include:

- Nursing case management
- Case management
- Pre-filled weekly "medi-sets"
- Pager-based medication reminder system
- Cash incentives
- Education groups
- Support groups
- Drop-in center
- Linkages to other services
- Assessment and referral for mental health and substance use disorders

Unlike the handful of other existing adherence programs in the United States, AP is not clinic-based. Because San Francisco is a resource-rich environment for HIV care, it was decided that the best use of AP resources would be to focus strictly on adherence and adherence support. The program maintains strong linkages with primary care providers and clinics used by AP clients.

There are needs here, and it [AP] needs to be right here. This is the center of muck and mire, and this is where it needs to be.

AP client

The AP center is accessible to clients five days a week, Monday, Wednesday and Friday from 9-5 and Tuesday and Thursday from 12-5. The center is closed to clients on Tuesday and Thursday mornings for regularly

scheduled staff meetings and case reviews. AP is located at 117 6th Street, in an active and impoverished inner city neighborhood. Clients can drop in for services or to ‘hang out’ any time during these hours.

Staffing

Current staff include:

- Medical Director (part-time)
- Nurse Manager (part-time)
- Nurses (2)
- Case Managers (2)
- Receptionist
- Consulting psychiatrist
- Pharmacist (part-time)
- Acupuncturist (part-time)

Job descriptions may be found in *Section 10: Adherence Support Staff*.

Budget

The annual budget of the center is \$450,000, funded through local general funds. As mentioned above, this funding mechanism has given the program considerable flexibility in designing and delivering services, because funding is not tied to patient load or number of services hours.

Client population

The AP program serves San Francisco’s urban poor living with HIV. The client base includes indigent, uninsured, homeless or marginally housed individuals with HIV, many of whom also suffer from mental health and/or substance abuse conditions. Advances in HIV therapy, such as ART, have generally been far less available to poor inner-city residents than to more stable and affluent populations (see Appendix A). Although medication

Demographic Characteristics of 105 AP Clients at Intake	
Characteristic	%
<u>Gender</u>	
Male	80
Female	10
Transgender	10
<u>Ethnicity</u>	
White	40
African American	35
Latino	11
Other	14
Median age	39 years
Ever injected drugs	71
Injected drugs past 30 days	29
Homeless 6 months or more in past year	54

adherence is challenging for people of all social classes, the urban poor encounter structural barriers, such as homelessness and shortage of food, that make adherence even more difficult. This is why the adherence support provided by Action Point is sometimes referred to as "the fourth antiretroviral."

Program concept and philosophy

Adherence is frequently addressed as a behavior that can be improved by improving individual habits or motivation. However, the urban poor contend with barriers to adherence which are beyond their individual control. Adherence occurs in a social and environmental context. It is difficult to take medication regularly when one is homeless, or hungry, or unable to access regular medical care.

... structural approaches require a shift in our thinking about how to change behavior. Many people view behavior as personally motivated or resulting exclusively from a person's conscious decisions. The role of the structural environment is therefore often overlooked. In this way, interventions may aim to change an individual's knowledge or motivations without also addressing the root causes or the context...

Esther Sumartojo*

AP is a *structural intervention*. Structural interventions seek to address barriers that are part of people's lives, but are outside their direct control.¹ For example, being homeless affects most people's ability to adhere to medication. By helping a person become housed, a provider addresses a major barrier to adherence that was beyond the individual's control. Structural interventions can also specifically change the structure of health care. For example, making services available on a drop-in rather than an appointment basis is a structural intervention which makes services more accessible and increases their utilization. Structural interventions seek to alter the context in which services are typically provided.

AP seeks to address and modify structural barriers in an attempt to enhance the likelihood and the success of individuals' effort to adhere to medication. The program also provides individual-level intervention services such as education, health care, encouragement and support.

¹ Blankenship KM, Bray SJ, Merson MH. Structural interventions in public health. *AIDS* 2000;14 Suppl 1:S11-21.

* Sumartojo E, Doll L, Holtgrave D, Gayle H, Merson M. Enriching the mix incorporating structural factors into HIV Prevention. *AIDS* 2000; 14 Suppl 1: S1-2

AP has adopted a *harm reduction* philosophy for working with clients. Harm reduction first arose as an alternative to abstinence-based treatment strategies for drug users. Realizing that many people are unable to successfully stop using drugs, harm reduction seeks to help people reduce drug-related harms. For example, needle exchange reduces HIV transmission and education on injection hygiene reduces skin infections.

As a general health promotion strategy, harm reduction is a non-judgmental, incremental approach to behavior change. The idea is to accept people "where they are" and to support them in making steps toward improving their health. Harm reduction actively involves clients in problem-solving, acknowledging that they are often the best experts on how to make changes in their own lives.

One example of harm reduction as enacted by the AP program: a client in the program was an active alcoholic who wanted to be on ART, but he did not want to stop drinking. His alcohol use affected his ability to be adherent. Rather than insist he give up alcohol before starting treatment, the program enlisted the help of staff at the client's favorite bar. The bartender would give the client his medication when he entered the bar every evening.

Because it [AP] helps you get grounded... Havin' somebody there no matter what your life is like. There was no prejudice shown. So it helped me.

AP client

What happens is that when you start treating people and you make their lives better -- in incremental ways -- sometimes in big incremental ways like getting them housing, they start feeling better about themselves. What happens when people start feeling better about themselves? They start doing things for themselves.

AP provider

Section 2: Adherence and Adherence Support

Action Point is a medication adherence support program. *Medication adherence support* refers to an array of strategies and services to assist people in taking medications as prescribed. The type and level of support needed varies by person.

What is adherence?

To adhere means "to stick." In the context of health behavior, adherence means to follow, or stick to, a prescribed health regimen. A prescribed health regimen could be a special diet, abstinence from certain drugs, an exercise regimen, or a medication.

Medication adherence means to take medications according to prescription. Many chronic illnesses are treated with medication. Diagnosing the illness and identifying the appropriate medication are the first steps towards effective treatment.

However, an equally important component of treatment is medication adherence. Even the most effective medication will not work if the patient does not take it. People tend to assume that taking medication as prescribed is a simple task when, in fact, it is often difficult. This is particularly true of ART, which often requires taking many pills at specific time intervals.

That's the only obstacle – that there's so many pills. They don't really make my stomach queasy anymore. They don't make me tired any more. It's just the point of just taking so many pills.

AP client

An earlier term for adherence is "compliance." Compliance means to act in accordance with the instructions of another, in this case the medical provider. This term has fallen out of use due to its authoritarian overtones. Another term, used primarily in the United Kingdom, is "concordance." Concordance is "a state of agreement or harmony" and is described as a participatory agreement between a patient and a health care professional about the patient's medication regimen (see box below).

Concordance is a new approach to the prescribing and taking of medicines. It is an agreement reached after negotiation between a patient and a health care professional that respects the beliefs and wishes of the patient in determining whether, when and how medicines are to be taken. Although reciprocal, this is an alliance in which the health care professionals recognise the primacy of the patient's decisions about taking the recommended medications.

Compliance to Concordance Partnership in Medicine Taking, London, UK³

AP is intentionally defined as an *adherence* support program. It strives to strike a middle ground between the idealism of concordance and the coercion implied by compliance. The program respects the autonomy and beliefs of individual patients. It also recognizes the responsibility of providers as ‘experts’ to assist clients in making good health care decisions. At AP, providers take an active role in making adherence possible for people with HIV by reducing barriers and providing support.

I worked with a lotta good people who cared about me. But all decisions that were made were my decisions... neither did they try to scare me. They just told me straight up, they didn't try to sugarcoat it... if I wanted it, it was there – it was up to me. Taking the meds is my decision.

AP client

What is Adherence Support?

Adherence support means to assist a person in following a regimen beneficial to his/her health. Adherence support can take many forms. For example, if you have a friend on a low-salt diet, you could support her by providing encouragement, helping her discover alternative spices or giving her a low-sodium cookbook.

Medication adherence support is an array of strategies and services to assist people in taking medications as prescribed. The type and level of adherence support needed varies by person and by life circumstances.

Adherence: To stick with a recommended health regimen.

Medication adherence: To take a prescribed medication as directed by a doctor.

Medication adherence support: Strategies and services that help people take medications as prescribed.

Studies show that non-adherence to medical regimens is common across illnesses and social classes². Over 50% of people do not take prescribed medications as directed³. In addition to the factors that cause most people to be non-adherent, such as

² O'Brien MK, Petrie K, Raeburn J. Adherence to medication regimens: Updating a complex medical issue. *Med Care Rev*, 1992;49:435-454.

³ Compliance to Concordance Partnership in Medicine Taking. Available at: <http://www.concordance.org>. Accessed March 3, 2002.

forgetfulness, busy schedules, and other priorities, the urban poor experience barriers such as homelessness, lack of food, concurrent health problems and drug addiction.

Why is adherence important?

The urban poor in the United States suffer disproportionately from chronic illnesses, such as diabetes, hypertension and HIV, which to be treated require ongoing adherence to therapeutic regimens. As medication options have advanced, adherence has become an increasingly important public health issue. In fact, the World Health Organization has recently launched a project “to enhance awareness of poor adherence as a public health problem and to improve adherence rates worldwide.”⁴

As HIV increasingly becomes a disease associated with economic disadvantage and other social health problems, it will be essential to develop interventions and care support systems to enable patients... to benefit from HIV treatment advances.

Bogart, 2000*

In the case of HIV disease, ART has dramatically increased the survival of people with HIV infection. However, ART requires high levels of adherence to provide full medical benefit. Level of adherence to ART is strongly associated with reduced viral load and longevity.

In addition, scientists continue to debate whether poor adherence to ART can lead to the development of drug-resistant viral strains. Recent data suggest this may not be the case, but research is ongoing (see Appendix A).

⁴ World Health Organization. Adherence to Long-Term Therapies. Available at: http://www.who.int/ncd/chronic_care/long_term_therapies/index.htm. Accessed December 9, 2001.

* Bogart LM, Kelly JA, Catz SL, Sosman JM. Impact of medical and nonmedical factors on physician decision making for HIV/AIDS antiretroviral treatment. *J Acquir Immune Defic Syndr* 2000, 23;396-404.

Section 3: AP Program Eligibility and Intake

This section describes eligibility requirements and intake procedures for new AP clients. More specific detail about procedures can be found in the Procedures Manual, Appendix B.

Eligibility

Prospective clients must be HIV-positive, must have a CD4 nadir of less than 350 cells/ml and a viral load peak of greater than 50,000 copies/ml. They must be currently taking anti-HIV medications or opportunistic infection prophylactic medication or in the process of considering whether to take them. In addition, clients must not be currently accessing other medication adherence services in San Francisco.

Selection for Intake

Two new intakes are conducted each week, on Monday and Friday mornings. Potential clients are instructed to come into the AP Center before 10 am Monday. If more than one person arrives for an intake appointment, a lottery is conducted to determine which client receives an intake appointment that day. The other client receives the Friday morning appointment (see *Procedures Manual, Appendix B*).

Intake Interview

Each potential client is assigned to an AP case manager. The case manager first explains the AP program in general terms, then obtains the client's signature on a variety of releases and informed consent documents (Appendix C). In order to participate, clients must fill out the consent for AP services. Consent for other services are signed and provided within the limits specified by the client.

A case manager completes a computerized Client Information System (CIS) Profile with each prospective client (Appendix D). The CIS system shares information between AP, the San Francisco AIDS Foundation, the AIDS Health Project and Shanti. The CIS system promotes coordination of services and the efficient sharing of information between AIDS service programs. With consent, clients are also

The nurse, the social worker and the client all work together -- kind of coming up with an individualized type of plan as to how best increase someone's adherence or maintain adherence. And it's really individualized -- that's the whole point of the program.

AP provider

either entered into or updated in the REGGIE system, which is a city-wide system that coordinates HIV/AIDS agency services.

Some clients may already be registered in the CIS system. In this case, the Case Manager updates existing information and collects new information specific to AP services.

When possible, the RN assigned to the client attends the intake appointment. This reduces the burden on clients in terms of repeating information. At minimum, the nurse tries to sit in on the part of the intake interview that addresses medical issues.

RN Intake

After intake, the client meets privately with a nurse. The RN Intake focuses on medical history, HIV diagnosis and treatment history, past & current experiences with HIV medications (if any) and past & current experiences with side effects. AP nurses try to gain an understanding of client's beliefs and motivations regarding ART, and the difficulties that have experienced or may experience with adherence. The RN also completes a domestic violence screening. A copy of the Nursing intake form is included in Appendix E.

TB Clearance

Participation in the AP program is contingent on clearance for tuberculosis (TB) infection. This policy is vital to the safety of AP clients, as people with HIV are highly susceptible to tuberculosis and exposure could lead to an outbreak among AP clients and staff. To enroll, clients must have a non-reactive PPD within the past 30 days or a negative chest x-ray within the past ninety days. In addition, all clients that have a non-reactive PPD must also have a chest x-ray within 30 days of entering the program. PPD testing and/or x-ray can be coordinated with the client's primary care provider, or at the TOPS program. TB clearance must be renewed every six months through a routine symptom screen and skin testing. See *Appendix B: Procedures Manual* for the program TB protocol.

Section 4: Adherence Support Assessment

CIS intake data

The CIS intake is the primary tool AP staff use to assess potential barriers and facilitators of adherence. Along with the nursing intake, it provides a great deal of information pertinent to adherence. This section of the manual discusses common adherence barriers among AP clients, basic adherence issues such as motivation and living situation, and offers questions to supplement information gathered in the CIS interview.

Common adherence barriers

There are a handful of barriers to adherence which frequently affect AP clients, and which present considerable challenges to staff.

Lack of housing. Homelessness presents challenges to every aspect of a client's health and health care. Assisting a client in obtaining housing, although difficult, makes an immeasurable impact on their ability to adhere.

It's like ya have to be stable, ya know -- in order to be stable I gotta find me a permanent place... ya know I'd have a place to put my medication... I could lay down from the side effects and all that.

AP client

Substance use. Substance use can create a level of chaos in client's lives that makes routine adherence difficult. Working with clients to reduce and/or stabilize their substance use promotes adherence. If a client tends to binge on drugs at certain times (for example, on 'check day') or when there are certain 'triggers', work with the client to develop contingency plans for these occasions. For example, perhaps someone can call the client and remind him to take his medication the first few days after payday. Occasionally, if

There's times that I'll just walk out the door and it'd be Payday -- I just forget. Not on purpose -- my mind be on *money*... I be on the run. Once I start usin' drugs I be on the run.

AP client

The most difficult thing is engaging clients around what is really affecting your adherence -- when it's related to substance abuse, specifically.

AP provider

someone is a routine user of drugs (e.g., regularly injects heroin), tying medication-taking to the drug routine may be helpful.

Violence. Interpersonal violence is another common adherence barrier among AP clients. Abusive relationships impact a person’s self-esteem, make the living environment chaotic and disrupt routine. Assisting clients in addressing abuse in their relationships promotes adherence both by enhancing self-esteem and by reducing personal chaos in their lives.

Appointments for social and medical services. Ironically, sometimes being well-linked to social and medical services negatively impacts a client’s adherence. Appointments for services and care are time-consuming and disrupts a client’s routine. They can also be upsetting for clients if they don’t feel their needs were met. Keeping track of appointments in the care plan and strategizing with clients about how to time their dosages on these days is one good strategy.

I make so many appointments I forget I make ‘em. I overbook myself – my services, you know.

AP client

Motivation for seeking ART and adherence support

Probably the single most important piece of information to help determine readiness for ART is: Why is the client seeking ART? There are a variety of possible reasons.

- The client wants to feel better
- The client fears the HIV disease is progressing
- The client’s doctor said it is a good idea
- The client’s new lover is on ART
- The client just received an HIV-positive antibody test result

Each of these reasons provides important information that helps determine readiness for treatment. For example, the client’s doctor may have recommended treatment, but does the client herself want it? If not, she may not be ready for a difficult medication regimen. The client who wants to feel better may need to be educated about the initial side-effects when beginning therapy. The newly positive client may need more information about HIV, as well as viral load and CD4 testing.

A lot of people didn’t stay. A lot of people came and said, “my doctor told me to show up here.” Came in, looked around, had a conversation – maybe even had three conversations – and left.

AP provider

There is no formulaic response to the issue of motivation. It is not that some motivations are "right" and others are "wrong." However, a discussion regarding motivation will assist the provider in assessing the client's attitude towards treatment, which can help shape the adherence care plan.

What does the client think the benefits of the medications will be? A client may have realistic or unrealistic expectations concerning ART. Talk to the client about what s/he sees as the potential benefits of medication. Provide education as needed. It is important that clients have at least a rudimentary idea of what the medications do and the commitment involved in taking them.

Previous experiences with HIV medication. If the client has previously taken HIV medications, including ART or AZT, ask him to describe his previous experience in detail. Why does s/he want to try medications again? Try to assess if the client's previous problems adherence still exist, and what may be ameliorating factors.

Reason for seeking adherence support. Investigate why the client is seeking adherence support. Is it because was unable to adhere to ART before? Did a case manager recommend it? Ensure that the client has realistic expectations of what the program offers.

It's about bein' able to have a schedule and keep to it no matter what. That's why I came to this program.

AP client

In addition to the CIS medical narrative questions, the following questions may be helpful:

Questions regarding motivation for treatment & adherence support

1. Why are you interested in ART right now?
2. What are you hoping the medications will do for you?
3. Have you ever taken any HIV medications before? If so, what difficulties did you have with them?
4. This program provides support to people trying to take HIV medications. Why are you looking for adherence support?
5. What kind of help do you think you need to be able to take HIV medications?

Living Situation and Basic Needs

A basic understanding of the client's living situation aids in the development of an effective adherence support plan. It is also important to assess how challenging it is for the client to fulfill his basic needs, such as food and shelter. You may want to ask the following questions in addition to the Housing section of the CIS:

A complete list of adherence assessments questions, by topic, is available in Appendix G.

Questions about living situation and basic needs

1. Are you currently homeless?
- IF YES,
 2. Where do you usually sleep at night?
 3. Where do you keep your stuff?
 4. Do you have a place to "hang out" if you're not feeling well?
 5. Do you have easy access to a bathroom?
6. How many meals a day do you usually eat?
7. Can you always get food when you're hungry?
8. Can you always get water or something to drink?

Identify Routine and Disruptions to Routine

Routine is a powerful ally of adherence. Even though the life of a client may appear unstable, she may have regular routines she follows in order to get her needs met. By the same token, disruptions to routine can disrupt medication-taking. These disruptions may include running into friends unexpectedly, getting "high", being picked up by the police or being held up in line for free food. Some disruptions may be predictable, such as drug binges on the day the General Assistance check arrives. "Contingency plans" can be made for these somewhat predictable breaks in routine.

Action Point's made it easier for me to take my meds, 'cause they got me down to a routine now.

So if they [client] do really well with remembering their pills in the morning but they always forget at night – try to figure out what prompts them in the night. Do they brush their teeth before they go to bed? Do they always pee before they go to bed? And sometimes it's hard to narrow it down 'cause people's lives are really chaotic so, it's not easy -- it's not always an easy thing.

AP provider

Questions about daily routine

1. Do you have a routine you stick to most days? Tell me what you do in the:

morning:

afternoon:

evening:

night:

2. Do you sleep during the day? If so, when?

3. Do you watch the same TV shows daily?

4. Do you use drugs or alcohol regularly?

IF YES, Do you have usual times of day you drink or use?

5. Does your routine ever get disrupted? By what?

6. Are there days of the week or times of month when your routine is different?

Competing life priorities

People living in poverty often have difficulty meeting their basic survival needs. In addition, competing life priorities, such as the need to procure drugs, and competing health issues, such as mental illness, can affect medication adherence.

There's a lot of people who come through here that really try. And they have a lot of problems being here but they really, really try and they wanna maintain the best possible health they can. But there's just other things goin' on.

AP provider

Identifying these priorities and issues in a non-judgmental manner is part of a good adherence support assessment.

Questions about competing life priorities

1. Do you know most days where you are going to sleep and eat?
2. Do you spend a lot of time working or "hustling" for stuff you need? (for example, money, drugs, food or a place to sleep)
3. Are you on probation or parole? Are there any warrants out on you?
4. When you're going about your daily life, do you ever have hassles with police? How often do you get 'shook down'? What usually happens?
5. Do you ever get 'picked up' and taken into jail? How often? How long do they usually keep you?

IF USE DRUGS OR ALCOHOL,

6. Do you use drugs/drink most every day?
7. Do you use them (or use them more) at certain times of the month? When?
8. Is your memory or ability to plan affected when you're using?
9. Can you think of ways to remember to take your medication when you're 'high' or drunk?

Social Support

Friends and family can be a significant adherence support resource. They can provide encouragement, reminders and sympathy. They can also provide care when AP clients are ill or suffering medication side effects. In addition to the questions in the Social Support section of the CIS, some of the following questions might be helpful.

Every time I take pills it might be that I have a terminal illness -- a couple of 'em for that matter. I got Hep-C also in there.

AP client

We've always had a number of people with mental health issues above and beyond your basic like depression and anxiety, but schizophrenia and other psychotic things. And it seems like we've done well for them.

AP provider

Questions about social support

1. Are there people in your life who help you out regularly? Are there people you help out?
- 2.. Are you "out" to most of your friends about your HIV status?
3. Do you have friends or acquaintances that take ART?
4. Are there certain people that you see every day (friends, partners)?
5. Can you think of anybody who could help remind you to take your medications?
6. Is there somebody who could help take care of you if you were sick?

Non-HIV related health issues

Urban poor populations are characterized by a number of chronic diseases in addition to HIV. Asthma, high blood pressure and diabetes are all common. Mental illness is common as well. In terms of medical management, it is obviously important to identify patients' co-morbidities. But it is important from an adherence support perspective as well. For example, a client who regularly takes blood pressure medication may do well with an ART regimen that works on the same schedule. Clients with mental illness sometimes need to be stabilized on psychiatric medications before they can succeed at ART adherence. Depression in particular has been correlated with non-adherence in several studies (see Appendix A). Coordinated care for all health issues will improve adherence.

Every time I take pills it might be that I have a terminal illness -- a couple of 'em for that matter. I got Hep-C also in there.

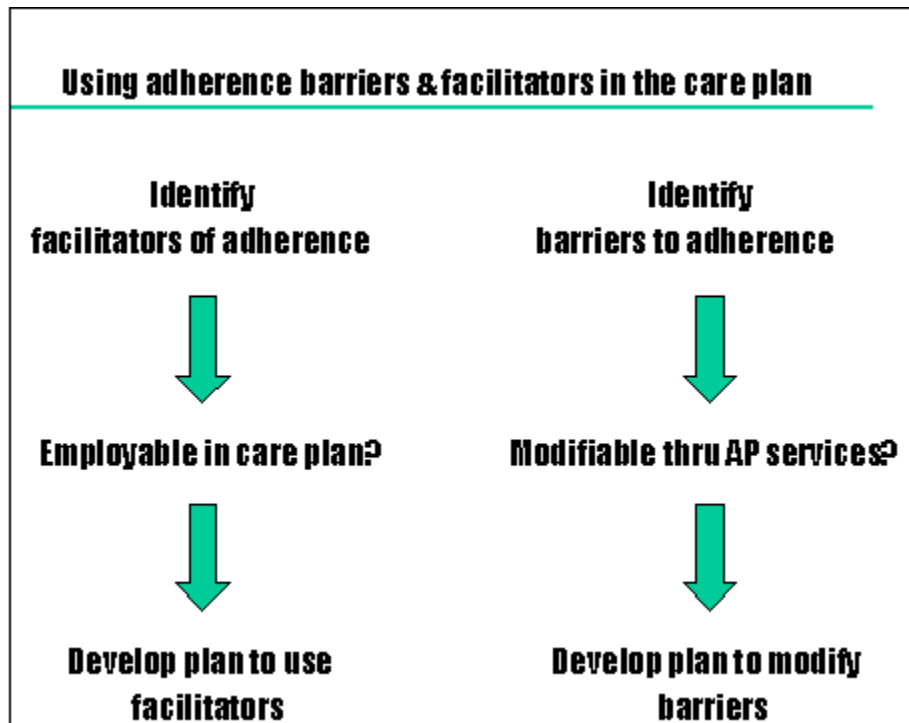
AP client

We've always had a number of people with mental health issues above and beyond your basic like depression and anxiety, but schizophrenia and other psychotic things. And it seems like we've done well for them.

AP provider

Synthesizing information from the assessment

The intake and assessment process provides a flood of information. The following questions assist in sorting which are pertinent to the clients adherence plan: Which factors in the client's life are likely to assist him or her in adherence? Which are likely to be barriers? Are those barriers modifiable, using tools obtainable through the AP program? Is further investigation and discussion needed?



Section 5: Adherence Care Support Plan

Based on the comprehensive assessment, an Adherence Care Support Plan is developed for each AP client (Appendix F). The purpose of the Care Plan is to create an individualized program for how the client will work with AP staff towards the goal of medication adherence. In consultation with the client, this plan is initially filled out by the Case Manager, and then completed in regard to medical issues by the Nurse.

The care plan addresses psychosocial, medication management and other health care issues. Frequent elements of an AP client care plan include a daily medication dosage schedule, frequency of visits to the center, appointments to make or attend for health care, and client plans to obtain supportive services or attend groups. In addition, there are standard elements of the care plan including:

- Providing proof of TB clearance every 6 months
- Regular visits by client to his/her primary care provider
- Regular lab testing as required by primary care provider
- Regular meetings with AP nurse and case manager

The Care Plan should be considered a working document, subject to continual updates and revision. This is especially true of a new care plan, when both the client and the staff are learning how the client's needs and AP program services best 'match up.' When a client presents difficulties in achieving his/her goals, the client meets with staff and they revise the Care Plan as needed. A sample of an ongoing Care Plan is presented in Appendix F.

The fact that you have to come in here once or twice a week -- you know that's my agreement...with other people it's gonna be different. But it just keeps me -- it helps to keep me -- focused. Everyone here is real nice and knowledgeable.

AP client

We try to really collaborate on our care plans with clients and really work together to try and figure out how we can best support the client together from a medical social work perspective.

AP provider

Section 6: Medication Management

AP nurses spend a great deal of time working on adherence medication management with their clients. Medication management should always be included in the care plan. This section presents some of the core issues in providing support regarding medication taking.

Readiness for ART

Many clients are not ready to try or re-try ART when they first enter the program. Time spent initially thoroughly exploring and strategizing around adherence issues enhances the chances of success once medications are started.

It's been discussed that it's okay not to rush. And not to do things partly. I've been asked to really, really, make sure that I'm ready before I start takin' them. And there's no immediate hurry to start taking them...

AP client

Practicing the adherence regimen

AP nurses often encourage clients to practice a new medication schedule with vitamins or OI prophylaxis such as Trimethoprim/Sulfamethoxazole (Septra/Bactrim). While a client may believe a proposed regimen is feasible, there is no substitute for a 'test drive.' The trial period provides valuable information about day-to-day problems that arise with adherence. Sometimes these require only simple modifications in the regimen, like a small pill box for the client to carry containing his mid-day dose. Sometimes a different regimen needs to be discussed with the patient's physician.

I started this program just doin' the Septra and a vitamin -- just to get me in the habit of taking a pill in the morning and a pill at night... I actually did that for quite some time -- probably a good two months -- before I actually started the HIV meds.

AP client

Pharmacy support & Medi-sets

Through its collaboration with a nearby pharmacy, AP provides 'one-stop shopping' for client medications. All medications are organized in a medi-set. Clients don't have to struggle with juggling pill bottles, trying to remember which pills were taken and which were not, or which need to be refilled when. Encouraging clients to take advantage of this option helps with medication management.

Back-up medications

It is common for AP clients to experience unpredictable events, such as theft, loss of housing or loss of possessions. AP keeps back-up medication on-site for clients so that these events are less disruptive to medication adherence.

Non-HIV medications

An important feature of medication management is coordinating the clients HIV and non-HIV medications. With the exception of opiate-based pain medications, all of a clients medications can be included in the mediset provided by AP. (Opiates are not stored at the AP office to reduce the likelihood of a break-in). Sometimes it is important to stabilize clients on other medications, for example psychiatric medications, before beginning ART.

Side effects

The last time the doctor put me on Sustiva it made me feel like I was on "hop" [heroin] or something -- it made me sick. And it's supposed to kill the HIV but I think it woulda killed me if I kept on takin' that -- so I stopped takin' that shit.

AP client

... just being gentle and supportive and saying, "I know it's hard. I know it's hard to take these medications. I know you're suffering with nausea. Let's treat it. Let's treat the nausea."

AP provider

Unpleasant side effects from medications are a major issue in ART adherence. It is important to educate clients about the side effects they can expect to experience with various medications, and how long they will last. It may be possible to select or change to medications that have the side effects a client finds most tolerable. For example, Nelfinavir may be a poor choice for a client living in a car as diarrhea is a frequent side effect of this protease inhibitor. Extra support should be given to clients during the period that side effects are at their worst. In addition, ancillary medications, such as anti-diarrhea medication, should be provided when appropriate.

Simplification of regimen

Working towards the simplest medically viable ART regimen facilitates adherence.

Some people we were able to get orders for their doctors to have them take medications once a day -- it's not really recommended by the CDC but people are doing it experimentally. That's helped quite a few -- two or three -- that I can think of...just that once-a-day dosing.

AP provider

This requires communication between the client, the nurse and the client's primary provider.

Stopping medication

Sometimes personal crises, such as loss of housing, create a level of instability in clients' lives that undermines adherence dramatically. Scientific studies support the idea that it may be better to discontinue all medications simultaneously rather than adhere poorly to a prescribed regimen. It is sometimes advisable for clients to stop taking medication altogether during times of crisis, when adherence is poor. A target date to restart medication can be incorporated in the client's care plan.

If a client has stopped takin' the meds -- whether it's related to relapse or being homeless or mental health issues... I usually don't try and push them back on their meds but I really try to focus on what's going on. And then addressing, are they ready to start back on their meds?

AP provider

Communication with pharmacy and primary care provider

Effective medication management often requires AP nurses to act as liaison between the program and primary care providers, as well as pharmacy staff.

If I came in, and I wasn't feelin' good the nurse would take my temperature, check my blood pressure, and things like that. If something was wrong she'd get on the phone to my doctor and call him, and say, "You need to see L. here."

AP client

Section 7: Adherence Case Management and Harm Reduction

Case management services at AP differ from ‘traditional’ case management. While case managers must have strong basic training and skills, they must also be able to orient their services towards the goal of adherence support and to integrate harm reduction principles into their work. Harm reduction is consistent with many of the central tenets of case management, such as being client-centered, working with clients from ‘where they are’ and involving clients in the process of change. This section summarizes some of the unique challenges and techniques in providing adherence support case management from a harm reduction perspective.

Importance of being non-judgmental

AP case managers strive to create a safe and trusting environment for clients so they can be open about the issues that affect their adherence. Only by being aware of these issues can AP case managers work effectively with clients to address them.

Well first of all they're very non-judgmental. I didn't have to be concerned about if I'm upset, I couldn't come in, ya know. No matter how I was, they still let me come in, you know. They never make you feel bad.

AP client

I'm really a believer in suspension of judgment. I think if one of our clients gets a sincere feeling about that, the more honest the client can be with you about the fact that they're having trouble being adherent -- the better the relationship is gonna be.

AP provider

Supportive counseling

Taking ART is difficult and draining, particularly when a client is already coping with challenges such as addiction, substandard housing and poverty. In addition to working with clients to identify and address barriers to adherence, AP case managers provide ongoing supportive counseling to clients.

I think that we have developed a safe place for clients to feel like they can come and talk, which in the long run helps them get to a place where they can feel ready to take care of themselves.

AP provider

Crisis intervention

Clients often come into AP with a variety of crises, due to medical complications, drug use, or loss of housing. Providing emotional support or resources such as housing vouchers can help alleviate clients' immediate distress. An important component is to make a follow-up plan with the client to come in for more case management once the crisis has resolved. Case managers consult with staff at the AIDS Health Project if a client seems to be a danger to himself or others (see *Section 8: Linkages and collaborations*). In addition, medical providers are often consulted to determine if a client in crisis needs to be escorted to the Emergency Room.

Drug use

Most AP clients have substance use issues. Working with clients who use drugs poses special challenges. For example, drug-using clients cannot be linked with services that require

I woulda never been in recovery if I wouldn'ta came here. I woulda never have thought about goin' through recovery because I would not know the important things about HIV meds. I would not have known of the resources available for me to get off the drugs, and continue takin' my meds.

AP client

abstinence for participants. Clients who relapse in drug use are sometimes ashamed to return to the center for services. AP case managers strive to establish open and non-judgmental communication with clients about their drug use, and try to work with them on realistic plans to manage drug use to minimize its impact on adherence.

Establishing Boundaries

While case managers at AP practice harm reduction, they also inform clients of the rules of conduct in the program which include no physical or verbal abuse, no use of illicit substances on site, etc. (see Appendix C). Clients that violate the rules of conduct in the program may have a behavioral contract established, may be restricted from service or may be dis-enrolled in the program dependent on the severity of the behavior. Clear behavioral boundaries are as essential to a successful harm reduction program as accepting that change happens incrementally.

Section 8: Linkages & Collaborations with other Services

San Francisco is a relatively 'resource-rich' environment. AP relies heavily on outside resources in to help meet client needs and to improve AP services. This section is not comprehensive, but rather provides a 'short list' of most commonly used referrals at the AP program.

They seem to be lookin' out for my best interest, ya know -- they take care of me, ya know. Whatever is entailed -- whether it's housing or do I need a therapist, do I need some kinda special help, do I need to go to a treatment program or whatever. They offer it to me and if I decline then they don't pressure me.

AP client

Forensic AIDS Project (FAP)

AP collaborates with FAP for follow up of AP clients who become incarcerated. In addition, FAP refers soon-to-be released clients to AP and FAP staff accompanies clients to their initial AP visit.

Tuberculosis Outreach Prevention Services (TOPS)

AP clients are often referred to the TOPS program in the Tenderloin for TB clearance. Some AP clients receive TB medications from the TOPS program; AP provides directly observed therapy to these clients and keeps TOPS staff informed of their status

AIDS Education and Training Center (UCSF)

AETC provides training to AP staff monthly. This training is usually case based. AETC trainers also keep staff apprised of ongoing developments regarding HIV/AIDS and ART.

AIDS Health Project (AHP)

AP clients requesting mental health services are most frequently referred to AHP, which provides individual and group therapy. In addition, the AP program uses AHP's crisis team services a client may be suicidal or needs to be assessed for possible involuntary commitment (5150).

The Shanti Project

Shanti provides emotional and practical support services, such as peer advocates, transportation services, and support groups. In addition, they organize a variety of recreational activities for people with HIV, such as movie nights, luncheons, tickets to special events, art classes. In addition, Shanti has a lounge where clients can drop in and relax.

Bay Area Addiction Research and Treatment (BAART)

Some AP clients receive methadone replacement therapy and case management at BAART. With client permission, AP staff coordinates care with BAART case managers.

Rite Aid pharmacy

The Rite Aid pharmacy at Van Ness and Market fills the prescriptions for most AP clients. (See *Section 6: Medication Management*).

Continuum

Continuum is a support program for people living with HIV based in the Tenderloin. Clients sometimes transition from Continuum services to AP, and vice versa, depending on their needs. AP and Continuum collaborate during the changeover to assure a smooth transition for the client.

Health at Home

AP clients who are part of the community health network, and who are unable to attend clinic, are eligible for health home services. These services typically follow hospital discharge. Health at Home provides nursing services, social work services and home aides who will assist with cleaning and laundry. They also offer physical, occupational and speech therapy.

In-Home Support Services (IHSS)

Clients are linked to his service through the San Francisco Department of Human Services. IHSS will provide an in-home assessment to see what household chores clients have difficulty performing. They will assist w/ cleaning, laundry, grocery shopping.

Section 9: Adherence Support Tools

Drop-in Access

Many AP clients have difficulty keeping appointments. For this reason, the program is open for drop-in five days a week. When a client's case manager or nurse is busy, the client can either wait until they're free or see another nurse or case manager.

...they're real good about not saying, "Oh you had to be here at this time." You know, they're always welcoming -- if I don't come in on a day that I was supposed to come in, I can always come in on the next day or whatever.

AP client

Medi-sets

With their consent, clients' prescriptions are filled and placed in weekly Medi-sets by a nearby pharmacy and delivered to the AP center. Most clients pick up their filled Medi-Sets weekly. Back-up Medisets are also kept in case a client experiences loss or theft of their medication. Clients also have the option of picking up their medication on a daily basis from the Center on weekdays.

"For the medication they give me this Mediset... it doesn't look like as many pills as it does in the bottles."

AP client

Pagers & watches

Pagers are available to clients to remind them of medication dosing times. AP uses a web-based, alphanumeric pager system that beeps them and gives a short message, for example "Hello Fred. Time to take your medications." Loss of pagers is a common problem. A client may receive a replacement pager after a one-month waiting period, and after that at the staff's discretion. Program policy on pager availability is described in the Procedures Manual (Appendix B). For clients who prefer not to use a pager, watches with alarms are available.

Incentives

A \$10 weekly incentive is available to clients for the first 13 weeks they attend the program. Because virtually all AP clients are poor, the incentive helps them overcome initial barriers to participation. The short-term incentives help recruit and engage people in the program, so that they develop relationships with staff and get connected with adherence support services.

Procedures for handling cash incentives are specified in the Procedures Manual

(Appendix B), and in *Section 11: Program Challenges and Lessons Learned*.

It's like, "Ten dollars a week, wow -- to take my meds. Yeah!" So I thought that was pretty cool.

AP client

I don't come down and take meds for the money -- but money's good to have on Mondays [laughs].

AP client

Support and Education Groups

Weekly support groups and monthly educational video groups are held for clients. These groups provide a place for clients to learn more about HIV and ART, and a place to talk about difficulties with adherence with other AP clients. The groups last about an hour and food is provided.

Time, Respect, Relationships

Frequently, the single most important adherence support tool is the relationship developed between a client and the nurse or case manager. People who are poor often have had unpleasant experiences in the health care and social service systems: long waits, rushed appointments, bureaucratic hassles, staff who are disdainful regarding drug use and other non-conformist behavior. It may take time for clients to trust the services and staff at AP.

Well, first of all you have to respect the client, you know, and think that, ya know, we could be the clients -- I mean, it could happen to us. So you know, I think it's very important to have some compassion for these clients.

AP provider

I think what AP has done and will continue to do I hope better than most other programs that I've ever been involved with, is just loving people enough so that they feel that they're valuable. And that is virtually unmeasurable -- and probably the most important thing.

AP provider

Adherence is often about blending a complex life with a complex medication regimen. One important thing AP staff offers in this endeavor is time. Even among people who are insured, appointments with medical practitioners are often limited to 10 minutes every 3-6 months. At AP, nurses and case managers try to spend as much time with the patient as the patient needs, as often as needed. A client may need to speak with a case manager several times before she is comfortable disclosing the extent of her drug use, for example. Or a client with dementia may need several minutes to answer a nurse's fairly

... they have answered all my questions and they have taken time. They have taken time out and sat down to meet with me. And they'll ask me, "P., how's everythin' goin'?" Do you have a question before we proceed with our meeting?" "Yeah." I say, "I wanna know this -- what's goin' on? Why am I sick?"

AP client

So if you find somebody who's really behind you then they're really behind you. So I know she's [AP nurse] behind me so I trust her completely.... If she gave me some medicine to take I would take it -- I wouldn't think nothin' of it. But I don't usually take medicine that doctors give me 'cause I know the history of White doctors and Black folk.

AP client

simple question about side effects. Effective adherence support requires an in-depth understanding of clients' lives, which can take significant time, number of encounters and patience to develop.

It is important to show regard and respect for clients. AP staff express interest in the client as a person, use non-judgmental language, make eye contact and supply positive feedback.

As a consequence of time and respect for clients, AP providers develop relationships with them. Despite repeated proof that the relationship between the patient and provider is key to optimal health care, their development is not supported by most health care systems. The time and respect devoted to clients at AP is perhaps the most important structural intervention of all. Both providers and clients attest to the importance of an ongoing relationship in terms of promoting trust, and supporting adherence.

In addition to time, a key factor in the development of productive client-provider relationships at AP is the dedication of the staff. AP staff enjoy community-oriented health work. They like to work in non-traditional settings and they like the client population. This comes across to clients, who often have great affection for the program.

Section 10: AP Adherence Support Staff

AP staff work as a multi disciplinary team to provide health and adherence services to clients. The staff has two weekly meetings, one to discuss programmatic issues, such as the development of a client education curriculum, and one for case reviews. Each client's case is reviewed at least monthly. Ongoing in-service trainings are provided by the AIDS Education Training Center and by other providers in the City.

Equally as important as the meetings is the ongoing, daily communication and coordination between staff members. Adherence support requires a collaborative effort on the part of clients, nurses and case managers.

Meaningful assistance of San Franciscans living with HIV will require a multidisciplinary team approach, bringing together physicians, nurses, community health outreach workers, treatment advocates and social workers as the critical partners in an individualized plan of care.

**Recommendation of the Subcommittee on Adherence
Mayor's Summit on HIV/AIDS, January 1988**

We're constantly meeting so we're all sort of on the same page of what we need to get done. ... we spend a lot of time actually, constantly, trying to improve the program and get everything working together.

AP provider

Receptionist

The full-time receptionist provides administrative support to both clients and staff of the program. He greets and triages clients, giving them general information and directing them to appropriate services. He maintains a database documenting clinical data and use of services for all clients. He also maintains and updates the web-based pager reminder system.

The receptionist manages the office, carrying out duties such as ordering supplies, overseeing equipment maintenance, and coordinating with other agencies that use the office space. An essential role of the receptionist is to make clients feel welcome at the center and to demonstrate interest regarding their well-being and their participation in the program.

The front desk person's actually been really instrumental in our program -- knowing clients really well and being very conversational with them in the front, keeping people -- they don't mind waiting because they can talk to G.

AP provider

Medical Director

The Medical Director (15% time) supervises the Nurse Manager. In addition, he is responsible for assuring high quality service for all nursing and medical interventions. The Medical Director coordinates teaching sessions and instructs staff on the latest developments in HIV treatment and the intersection of HIV treatment and poverty. The Medical Director is the interface between community providers and AP staff to assist community providers to understand the goals, policies and limitations of Action Point and he/she encourages community providers to maintain the highest standard of care for HIV treatment among the urban poor clients of the program. The Medical Director attends weekly staff meetings and meets regularly with the nurse manager.

Nurse Manager

The Nurse Manager (60% time) develops and oversees the programmatic aspects of AP. She directs the activities of the multi disciplinary team. She acts as primary liaison to collaborating agencies, including the San Francisco AIDS Foundation, TB screening and treatment programs, and the pharmaceutical provider. She coordinates the health education curriculum and facilitates domestic violence screening. In addition, the Nurse Manager supervises the RN's and is responsible for planning, managing, delivering and evaluating nursing care administered and/or coordinated at AP. Nursing policies, procedures and standards are developed, maintained and updated by the Nursing Manager and she facilitates the continuing education of nursing staff. The nursing manager also provides direct care to a small number of patients.

Registered Nurse (2)

Two full-time RNs provides both nursing care and specialized adherence support services to clients. In conjunction with the client and the case manager, the RN assesses clients' complex medical, psychiatric, emotional and social situations to assist them in formulating a care plan to promote adherence to HIV medications. The RN coordinates clinical activities to ensure quality patient care, communicating with each client's primary health care provider, or assisting the client in obtaining a primary provider if necessary. The RN performs initial and continual assessment of client's health status,

I think that just the way that people feel in general often about nurses, and the way that they feel comfortable with nurses because of nursing just sort of being an intimate sort of profession sometimes... I think people really feel a connection. And I think that really does contribute to people feeling able to be honest about their adherence in a way that I think wouldn't happen if nurses weren't part of the program.

AP provider

immunizations, TB screening and dispensing of medications. The RN's meet frequently with clients to discuss their health and adherence concerns, triaging clients and helping them obtain urgent care services as needed. In addition, nurses communicate with the pharmacy and, if necessary, the patient's provider and the pharmacy to ascertain that medication needs are optimized and met.

Case Manager (2)

The CM (2 full-time) works with clients to resolve problems and needs that impact their ability to adhere to treatment. The CM conducts comprehensive assessments to determine each client's psychosocial, practical, and advocacy needs. In conjunction with the client and one of the AP nurses, the CM develops an adherence support care plan for each client. The CM implements the care plan and monitors the accomplishment of goals and objectives. The CM assists clients in developing skills and supports that promote medication adherence. The CM links the client to other services, facilitating those relationships as needed. The CM also facilitates health education and support groups. The CM provides ongoing supportive counseling to clients, as well as advocacy, crisis intervention and referrals.

They basically just see to a person and get to know a person – 'caues they readin' me pretty well [laughs].

AP client

Acupuncturist

Two afternoons a week, an acupuncturist & massage therapist offers services on a drop-in basis. At their request, clients use these services to relieve pain and discomfort, detoxify from drugs & rebalance energy.

Section 11: Program Challenges and Lessons Learned

As a new and innovative program, AP confronted unanticipated challenges and policy issues in its first two years. Many programmatic adjustments were made. This section summarizes some of the most significant.

Hours

Originally, the program tried to maximize accessibility by being open seven days a week. Utilization was low on weekends and the weekend hours were difficult for staff to accommodate. The center changed its schedule to be open on weekdays only.

In a way I wish they were open on Sunday, but I know everybody needs to rest.

AP client

Charting

A single client charting system was not in place with the program began. The case managers and nurses created and used different systems. This hindered communication between AP staff members and made client tracking difficult. The program now uses a single computer-based system that has improved consistency and communication.

Incentives

As originally structured, a \$10 weekly incentive was offered each client indefinitely during the time the client remained “active” in the program. They continued receiving the incentive for as long as they maintained minimum requirements for program participation. As the program became enrolled to capacity, maintaining this policy posed difficulties. Clients who didn’t really want to go on ART, or who were able to adhere independently, stayed in the program in order to continue receiving the weekly incentive. Fully subscribed, the program was unable to take new clients who needed adherence support.

In addition, some clients assumed that they would only receive the financial incentive if they reported adequate adherence to their medication regimen. This caused some clients to over-report their adherence rate, and made it difficult for staff to offer needed assistance to improve adherence. After much debate and discussion, AP staff decided to limit the incentive to the first thirteen weeks of program participation. Staff builds upon the relationship and mutual goals established during this period. In other words, the incentives are offered to recruit and engage people in the program but not to maintain their participation.

Collaboration between nurses and case managers

Nurses are trained to provide services according to the medical model, whereas case managers are typically trained in a social work model. These two approaches to adherence support are not always congruent. A social work model stresses client skill-building and independence to a greater degree than a medical model. In its first year, the program experienced some conflict among staff regarding how much to do for clients versus how much to expect them to do for themselves. Better communication between nurses and case managers, as well as a single charting system, has improved this area.

Program Graduation

There was considerable discussion among staff regarding whether AP clients should be expected to 'graduate' from the program after a certain period of time. That is, was the goal of the program to help clients achieve effective adherence *with the program* or effective adherence *on their own*? The policy now is that independent adherence is the ultimate goal for clients, but that there is no limitation on the amount of time they can spend in the program as long as they are working towards that goal. Staff collaborate with clients to establish a unique plan that may included a diminishing frequency of visits to the program until independence is achieved. The length of time necessary to achieve this independence may be indefinite. Graduation, like other aspects of the program, is voluntary and tailored to the needs of the client.

This is not a graduation program you're goin' through....I see it as a -- it's a -- it may be long-term for some, it may be short-term for others -- it's a program where individuals can get themselves in a situation where they can continually take their medicine, on a daily basis -- not missing any.

AP client